Physician's Note - Symptom & Treatment Checklist

My patient _____ DOB _____ has a diagnosis of Angelman syndrome, type _____ (ICD-10: Q93.51 Angelman syndrome) and requires individualized supports and services that are unique to this diagnosis.

Angelman syndrome (AS) is a rare, genetic disorder. Symptoms are caused by deficiency of a protein (UBE3A) in brain cells. The main features are seizures, intellectual disability, little or no speech, balance disorder and sleep disturbance.

For more information about Angelman syndrome, contact the Angelman Syndrome Foundation or the Foundation for Angelman Syndrome Therapeutics

Angelman syndrome Foundation 800-432-6435 | www.angelman.org

Foundation for Angelman Syndrome Therapeutics 866-783-0078 | www.cureangelman.org

The following supports and services are necessary for the health and safety of the individual you are serving:

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/ Support	Additional/Specific Instructions
❒	Anxiety	Excessive, disproportionate worry or fear that is triggered by any stressor or frustration. May lead to maladaptive behaviors.	In an attempt to reduce anxiety, speak calmly and explain what is happening and what to expect. In severe cases, psychotropic medication may be prescribed to reduce symptoms.	
❒	Aspiration	Taking food or saliva into the airway. May be followed by cough or throat clear, or may be silent (no overt symptoms). May put individual at increased risk for pneumonia.	Evaluation by a speech-language pathologist (SLP) or occupational therapist (OT). May require alternative feeding methods such as tube feeding or thickening of liquids taken orally.	
❒	Attentional Deficits/Short Attention span	Difficulty sustaining attention to tasks, especially non-preferred tasks.	Continuous reminders to return to task, which may need to be modified. In order to reduce frustration, anxiety and negative behaviors, assistance may be required for task completion.	
❒	Autism Spectrum	A neurodevelopmental disorder beginning in childhood and lasting throughout life. Includes a spectrum of conditions characterized by challenges with social skills, repetitive behaviors, speech and non-verbal communication. May co-exist with AS.	Treatments include intensive sustained special education programs and behavior therapy early in life. Available approaches include: applied behavior analysis (ABA); structured teaching; speech and language therapy (ST); social skills therapy and occupational therapy (OT). Medications may be helpful for symptom management.	
❒	Balance Disorder	Difficulty maintaining upright posture due to deficits of ability to control body in space. May appear as jerky motions or clumsy walking. May tire easily. See pronation.	Supervision required and supportive shoes recommended. Assistive devices such as braces, orthotics, walkers and gait trainers may be needed. Helmets may be needed for those at risk of falls. Wheelchair or stroller may be needed if balance disturbance is severe. PT to address underlying motor deficits. If braces used, skin should be monitored for blisters and/or rubbing.	
❒	Behavior Disturbance/ Maladaptive Behaviors	Engaging in unwanted behaviors such as hair-pulling, grabbing, pinching. A way to command attention or communicate. Aggression usually does not indicate intent to harm self or others.	ABA treatment approaches; redirection; explain why behavior is not acceptable; minimize engagement if challenging behaviors continue. Music therapy may help regulate mood and behavior.	

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❒	Communication deficits	Most individuals with AS are non-verbal and use a variety of alternative and augmentative communi-cation (AAC) methods.	Formal AAC evaluation by SLP/ assistive technology team. Ensure communication options are available, including gesture-based, picture-based, and electronic modalities.	See FAST Education Summit 2019 videos on communication, literacy, and language development https://www.youtube.com/c/CureangelmanOrg/playlists
❒	Constipation	Hard stools passed infrequently with difficulty and/or pain	Dietary modifications and stool softeners can be used to prevent the long-term sequelae (soiling, dysfunctional voiding)	
❒	Cortical vision impairment	Abnormal visual behavior cause by a problem with the brain (neurological) rather than structural eye disease	Treatment is directed at the underlying brain problem. Treatment should be directed by a vision therapist/specialist and may require increased lighting, larger objects and simplified views.	
❒	Developmental Delays	Lack of expected typical physiological development in childhood.	Therapies including PT, OT, oral motor therapy, ST and other modalities help promote attainment of maximum potential. Many such therapies can be incorporated into music, band, dance and art classes.	
❒	Drooling	Saliva flowing out of the mouth unintentionally, related to low oral muscle tone	Discussion with SLP or OT for oral motor exercises to assist with low tone. Bibs and bandanas to keep clothing dry. Medications to reduce saliva production can be used under physician supervision, but may adversely affect oral health.	
❒	Dysphagia	Difficulty chewing, swallowing or managing food textures	Supervision during meals and snacks due to choking hazard. Feeding and swallowing evaluation completed by SLP or OT to improve abilities and make appropriate recommendations.	
❒	Elopement	Leaving a setting without authorization; departure may threaten the safety of person or others. Generally occurs due to curiosity and failure to perceive danger.	Continuous monitoring (cameras may be considered). Alarms on all exits including windows and doors for those with a prior history of elopement.	
❒	Epilepsy	A neurological disorder in which nerve cell activity in the brain is disturbed causing seizures. Seizure types include staring spells, jerking movements, altered consciousness, and others.	Educate staff regarding seizure types and management. Treatment may include medications to control seizures, medically supervised diets, and implantable devices (vagal nerve stimulator). Neurologist should outline seizure action plan for school, including use of rescue medications by trained staff.	❒ ketogenic diet ❒ low glycemic index diet ❒ vagal nerve stimulator ❒ seizure action plan attached ❒ rescue medication for prolonged or repeated seizures provided to school ❒ medications (list)
❒	Excitable Personality	Trait of becoming excited too readily, easily overstimulated.	Provide calm environment to promote learning. Alternatively, if the child is overly excited, provide physical activity to allow an opportunity to expend energy.	
❒	Gastro-esophageal Reflux (GERD)	When stomach contents come back up into the esophagus, also known as acid reflux. May provoke gagging, retching or vomiting. Long-term risks of esophageal damage.	After eating a meal, avoid lying flat on the back; instead prop at a 30 degree incline. Dietary modifications may decrease reflux. Medications may be used to block acid production and/or improve motility.	
❒	Gastrostomy	A tube surgically placed into the stomach in order to deliver nutrition when feeding by mouth is not possible or advisable.	Typically needs no management during the school day. Mid-day medications delivered by G-tube should be done by trained staff.	

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❒	Hyperactivity	Being overly active, in constant motion.	Provide frequent breaks with physical activity to allow an opportunity to expend energy.	
❒	Hyperphagia	Abnormally increased appetite or inability to recognize satiety. May lead to obesity, a risk factor for many adult-onset health complications.	Continual supervision to control access to food. Teach portion control and modification of eating habits.	
❒	Hypotonia	Low muscle tone (tone = baseline amount of tension a muscle has at rest). Abnormally low resistance to passive movement.	Risk factor for falls and scoliosis. May contribute to drooling and motor delays. Often improves gradually with time and therapies aimed at strengthening. OT and PT should work together to create a plan of care that promotes development of the necessary skills for safety and mobility (i.e. sitting in a school chair, walking safely on school grounds).	
❒	Hypo-pigmentation	Reduced pigment in skin, hair and eyes causing fair complexion and sensitivity of the eyes to light	Sunscreen, hats, sunglasses and protective clothing.	
❒	Incontinence	Lack of ability to control bowels or bladder	Provide modality (see Communication Deficits) for individual to communicate need to use bathroom. Many individuals can stay dry and unsoiled if taken to the toilet at regular intervals.	
❒	Intellectual Disability/ Cognitive Deficits	Impairment of the mental processes that lead to the acquisition of information and knowledge and drive how the patient understands and acts in the world. Areas of cognitive functioning include Attention, Decision making, Judgment, Visual-spatial, Language, Memory, Perception, Planning, Reasoning.	Early intervention therapies may improve cognitive functioning. Supportive therapies for children of all ages, such as OT, PT, ST, ABA, Alternative and Augmentative Communication, Vision Specialist, Adaptive and regular PE, and adapted learning may improve functioning and provide additional skillsets for the child to master. Continuous supervision, ensure safe environment, teach safety protocols.	
❒	Mouthing	Exploring objects by oral manipulation. A normal phase of development that assists in the acquisition of oral motor skills. Can reflect a need for sensory input. Often creates increased drooling.	Providing a non-toxic sturdy chewing tool can help satisfy the need for sensory input and may help prevent chewing on unsafe items or clothing. Consult ST/OT for strategies to reduce mouthing which may impair ability to learn. Provide consistent supervision to ensure safety.	
❒	Pronation	Rolling inward of the foot, created by partial collapse of the arch of the foot when supporting weight. Individuals with AS often have excessive pronation which is a risk factor for other foot problems, such as plantar fasciitis.	Treated with supportive footwear and orthotics. Consultation with podiatrist may be beneficial. Braces may assist with pronation. If braces are worn, monitor skin for blisters and/or rubbing. PT can help to strengthen the foot to reduce pronation.	
❒	Scoliosis	Scoliosis is a lateral (sideways) curvature of the spine. Low muscle tone can contribute to scoliosis, which is an occasional symptom of AS.	Children should be monitored for scoliosis by their doctor. PT may help strengthen core and back muscles to correct and/or limit the curvature and allow for the child to sit properly in a school desk. Bracing may slow curve progression. Surgery may be needed in severe cases.	

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❒	Sensory-Motor Integration difficulties	Difficulty integrating all senses: visual, tactile, auditory, vestibular, and proprioceptive systems. Symptoms include decreased balance, impaired depth perception and emotional instability.	Treatment generally consists of Sensory Integration Therapy, with particular focus on integrating the visual, tactile, vestibular, and proprioceptive systems. Weighted vests and blankets as well as desensitization therapy may help. An OT can assist with classroom setup to provide the best setting for learning.	
❒	Sleep disorder	Symptoms include difficulty falling asleep or maintaining sleep. Sleep difficulties may impact ability to learn and overall health.	Consistent bed time and soothing pre-sleep routine. Medications to help sleep should be supervised by a physician. Some individuals require an enclosed bed or bedroom to prevent nighttime wandering.	
❒	Strabismus	Eye crossing or eye wandering; eyes not moving together. Includes inward (esotropia) and outward (exotropia) deviation.	An Ophthalmologist should be consulted. Glasses, patching, exercises, eye drops, and/or surgery may be prescribed. A Vision Specialist should be consulted to assist with in-school modifications.	
❒	Temperature regulation	Increased sensitivity to heat, possibly related to hypothalamic dysfunction; may cause sudden high fevers	Limit time outdoors when weather is hot; bring fan, mist bottle, cold drink, cooling vest when necessary; keep individual hydrated. Heat exhaustion and heat stroke require urgent medical attention.	
❒	Toe-Walking	Pattern of walking up on the balls of the feet, with heels off the ground. Can be a normal phase when some children are learning to walk.	When persistent, treatment with PT, bracing and casting may help. If severe, surgery to lengthen the Achilles tendon may be needed.	
❒	Water Affinity	Individuals with AS may be overly interested in water.	Continuous monitoring to prevent drowning when pools or bodies of water are nearby. Alarms, sensors and fences can be used to deter entry and alert adults.	
❒	Other:			
❒	Other:			
❒	Other:			

Physician's Signature: _____ **Date:** _____

Physician's Contact Info/Stamp:

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